

DOCUMENT RESUME

ED 473 535

EC 309 404

AUTHOR Edelman, Larry, Ed.

TITLE Parent Leadership Opportunities in Colorado: A Resource Guide To Let Parents of Children with Special Needs Know Where To Go To Develop and Apply Their Leadership Skills. Second Edition.

INSTITUTION Colorado State Dept. of Education, Denver.; Colorado Univ. Health Sciences Center, Denver.

PUB DATE 2001-02-00

NOTE 38p.; Edited with Wayla Murrow. Prepared by Early Childhood Connections, Colorado Department of Education and JFK Partners, University of Colorado Health Sciences Center. Also prepared by the Colorado Interagency Coordinating Council.

AVAILABLE FROM Colorado State Department of Education, 201 E. Colfax Ave., Denver, CO 80203. Tel: 303-866-6600; Fax: 303-830-0793; Web site: <http://www.cde.state.co.us>. For full text: http://www.cde.state.co.us/earlychildhoodconnections/docs/pdf/PL_Opps.pdf.

PUB TYPE Guides - Non-Classroom (055)

EDRS PRICE EDRS Price MF01/PC02 Plus Postage.

DESCRIPTORS *Agencies; *Child Advocacy; *Disabilities; Elementary Secondary Education; *Leadership; Leadership Training; *Parent Education; State Programs; Volunteers

IDENTIFIERS *Colorado

ABSTRACT

This guide provides parents of children with special needs information on opportunities to develop and apply leadership skills in Colorado. Introductory material considers the nature of parent leadership, the various roles of parent leaders, and ways to learn leadership skills. The next section describes specific parent leadership opportunities at the following agencies: Colorado Department of Education; Health Care Program for Children with Special Needs; Colorado Developmental Disabilities Planning Council; Children's Health and Rehabilitation Services; Colorado Community Mental Health System; Colorado Developmental Disabilities System; and JFK Partners, University of Colorado Health Sciences Center. Specific Colorado parent leadership development programs described include the Advocacy Project, the Coaching Project, Family Advocacy Curriculum, Mobilizing Families, Parent Encouraging Parents, and Policymakers. The final section describes other Colorado resources related to parent leadership development including Arc of Colorado, the Colorado Family Resource Network, Colorado Family Voices, and the Denver Community Leadership Forum. Remaining sections provide contact information for disability related interest groups, offer some strategies for participating, list publications, and describe the Early Childhood Connections statewide system. (DB)

ED 473 535

Parent Leadership Opportunities

In Colorado

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☒ This document has been reproduced as
received from the person or organization
originating it

☐ Minor changes have been made to
improve reproduction quality

• Points of view or opinions stated in this
document do not necessarily represent
official OERI position or policy

Second Edition, February 2001

A resource guide to let parents of children with
special needs know where to go to develop and
apply their leadership skills.

PERMISSION TO REPRODUCE AND
DISSEMINATE THIS MATERIAL HAS
BEEN GRANTED BY

N. Bolt

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)

1



cde

Prepared by
Early Childhood Connections,
Colorado Department of Education
Colorado Interagency Coordinating Council And
JFK Partners,
University of Colorado Health Science Center

EC 309404

Parent Leadership Opportunities In Colorado

Second Edition, January 2001

A resource guide
to let parents of children with special needs
know where to go to develop and apply their leadership skills



Prepared by
Early Childhood Connections, Colorado Department of Education
Colorado Interagency Coordinating Council
JFK Partners, University of Colorado Health Sciences Center

Larry Edelman, Editor
With Wayla Murrow

Please feel free to copy and distribute this guide freely to families and providers who would like to support parent leadership in Colorado.

For more information about this guide or to submit additions or corrections, please contact:

Early Childhood Connections
Colorado Department of Education
201 East Colfax Avenue
Denver, Colorado 80203-1799
(303) 866-6710

Contents

Introduction	4
What is Parent Leadership?	5
Parent Leadership Opportunities at:	
Colorado Department of Education.....	8
Health Care Program for Children with Special Needs (HCP)	11
Colorado Developmental Disabilities Planning Council.....	13
Children's Health and Rehabilitation Services	15
Colorado Community Mental Health System	16
Colorado Developmental Disabilities System	17
JFK Partners, University of Colorado Health Sciences Center	19
Colorado Parent Leadership Development Programs	
The Advocacy Project.....	21
The Coaching Project	22
Family Advocacy Curriculum	23
Mobilizing Families	24
Parents Encouraging Parents (PEP).....	25
Policymakers	26
Other Colorado Resources Related To Parent Leadership Development	
Arc of Colorado	27
Colorado Family Resource Network	27
Colorado Family Voices	27
Denver Community Leadership Forum	28
El Grupo Vida	28
Parent Leadership Training.....	28
Parent Surrogate Program.....	29
Parent to Parent of Colorado	29
PEAK Parent Center	29
Teamwork, Consultation, and Leadership Dialogues	30
Colorado Disability Related Interest Groups	31
Even More Opportunities for Parent Leadership.....	34
Some Strategies for Participating.....	35
Institute for Family-Centered Care Publications	36
About Early Childhood Connections.....	37

Introduction

The Early Childhood Connections staff of the Colorado Department of Education (CDE) and the Colorado Interagency Coordinating Council have a long-standing commitment to parent leadership in Colorado. There are at least two important reasons for this strong interest. The first is that parents of children with special needs often recognize that in order to be successful parents and advocates for their children, they need to embrace leadership roles. The second reason is the strong belief that parent leadership efforts are key to promoting inclusive communities and the provision of supports and services in natural environments. For both of these reasons, CDE has sponsored an initiative that supports parent leadership activities throughout the state. This resource guide, *Parent Leadership Opportunities in Colorado*, is one of many activities that is part of this broad leadership initiative.

Because, as a whole, they differ in their leadership interests, parents provide many different kinds of leadership, including: advocating for one's own child and family; being available to provide support to other parents and families; and working on broader levels on behalf of all children and families in a community, in a region, in a state, or throughout the country. The purpose of this guide is to let parents of children with special needs know where they can go to pursue their particular interests in developing and applying their leadership skills.

This guide aspires to provide information that is as complete and accurate as possible. Because new programs start up all the time and other information changes, it is assumed that this guide might very well contain some inaccuracies or omissions. Please submit any changes or corrections for future editions.

Please feel free to copy and distribute this guide freely to families and providers who would like to support parent leadership in Colorado. For more information about this guide or this initiative, please contact:

Early Childhood Connections
Colorado Department of Education
201 East Colfax Avenue
Denver, Colorado 80203-1799
(303) 866-6710

What is Parent Leadership?

Parents of children with special needs often recognize that in order to be successful parents and advocates for their children, they need to embrace leadership roles. The role of a parent leader is not easily defined. Because every family is unique, parent leadership is also unique. As families change over time, the ways that parents express their leadership also changes. Although there are countless ways to express parent leadership, there are several themes that are central to the vision of Early Childhood Connections' parent leadership initiative.

- ◆ Parent leaders recognize that parents are their children's best resources, that no one loves their children the way that they do, and that parents are their child's strongest advocate and decision-maker until the child can assume such responsibility.
- ◆ Parent leaders work on many different levels. Parents might express their leadership by:
 - advocating for one's own child and family;
 - being available to provide support to other parents and families;
 - working on broader levels on behalf of all children and families in a community, in a region, in a state, throughout the country or the world.
- ◆ Parent leaders advocate for inclusive communities and for services being delivered in ways that promote inclusion, and for the right of all children and adults to participate and contribute fully in their communities. Parent leaders communicate a vision of the rich possibilities that life offers persons with disabilities and their families.
- ◆ Parent leaders place a high value on building and strengthening communities.
- ◆ Parent leaders support the right of every family to have positive and healthy visions of their children from the beginning, and to have hopeful dreams of their family's future.

What Roles Do Parent Leaders Take On?

As well as being parents, parent leaders assume a variety of other roles, including:

activist	standing up to oppression and discrimination
advocate	being actively involved and persuading others to get involved
challenger	questioning how systems operate and encouraging others to think outside the box
change-agent	working on a systems level, be it local, statewide, or national to effect change
collaborator	reaching out to families, professionals, agencies, and other community resources to work as a team
community developer	working in positive ways to mobilize communities, maintain relationships, and develop resources
educator	teaching, training, dialoguing informally, and, in general, making presentations of all kinds to a wide variety of audiences, including professionals on their children's team
facilitator	helping groups to identify common interests and work together
framer	offering people a different framework from which to think about their issues
innovator	bringing new ideas to communities that might otherwise pass some areas by
life-long learner	acknowledging that as children grow, learn, and change, so too must their parents
listener	engaging in empathetic conversation
mediator	understanding what sometimes seem to be extreme views of passionate advocates and helping to find common ground
mentor and coach	supporting the leadership development of others
negotiator	being able to listen to diverse viewpoints, knowing their own "bottom-lines", where they are willing to give
participant	showing up at meetings and other places where parents' voices are needed
professional team member	working as a paid staff member
role model	demonstrating best practices in leadership and other areas
supporter	being available to provide support to other families, being a part of parent-to-parent networks
visionary	giving direction to programs and services

How Do Parents Learn To Be Leaders?

There is no guidebook for parents of children with special needs to learn how to be a leader. Parents have observed that they learn leadership skills through a variety of ways.

Parents learn leadership through their children by:

- advocating for inclusive communities, for appropriate supports in the community, and for their children's rights to participate fully in community life;
- taking charge in unfamiliar situations, rather than assuming that service systems will do everything;
- struggling for the best education for their children, negotiating both planning and mediation processes;
- problem-solving a complex maze of systems to gather the needed supports and services that don't often come easily;
- asserting their right to be decision makers for their children and families.

Parents learn leadership skills from others.

Parent leaders look to each other for validation, support, information, skills, and recognition. Parents learn leadership from their children, other parents, mentors, workshop leaders and trainers, professionals, persons with disabilities, and national leaders and visionaries.

Parents learn leadership skills in a variety of places.

Parents build leadership skills at parent-to-parent network meetings, informal conversations, workshops and training programs, planning sessions, advisory meetings, and at home every day.

Parents learn leadership skills by getting involved on a systems level.

Parents build leadership skills by accepting leadership roles and being an active participant and contributor in systems level change efforts.

Parents learn leadership skills by volunteering their time.

There are countless opportunities to serve on committees, advisory boards, as advocates for other families, and to participate in training programs. Many of these opportunities offer no direct financial compensation.

Parent Leadership Opportunities at the Colorado Department of Education

It is the Colorado Department of Education's (CDE) intention for all activities to have meaningful parent participation. Parents:

- are hired to be part of a CDE team – there is a Family Consultant position in the Special Education Unit and parents of children with special needs hold a variety of positions in Early Childhood Connections;
- participate in planning, advisory, and evaluation groups;
- participate in a variety of ways in funded projects;
- receive scholarships to attend national and statewide conferences; and
- present or co-present at a variety of meetings and conferences;
- participate, with financial compensation, in monitoring activities of local early intervention and school programs.

Among the opportunities for parent leadership roles within CDE funded activities are the specific ones described below.

Local Early Childhood Connections Programs

Parents might play a variety of leadership roles including:

- paid staff;
- members of the Local Council Board;
- volunteers in a number of activities such as parent-to-parent connections, and task forces, such as transition, developing community resources, etc.
- parent representatives (paid or volunteer) from another agency who collaborate with the Early Childhood Connections Program; and
- connections to programs related to Part C efforts, e.g. Family Support Services Programs, Preschool Advisory Councils, Welfare Reform activities.

For information about ECC programs, contact 1 (888) 777-4041 to be connected with the local Early Childhood Connections office in your area or visit the website at www.cde.state.co.us/earlychildhoodconnections

Colorado Interagency Coordinating Council (CICC)

Parents might play a variety of leadership roles including:

- general members;
- co-chairs of the CICC; and
- committee members for CICC sub-groups that parents who are not members of the CICC participate on, such as Individualized Family Services Plan (IFSP) Committee, Service Coordination Committee, Public Awareness Committee.

For information about the CICC, contact Susan Smith at (303) 866-6709.

Colorado Special Education Advisory Committee (CSEAC)

The mission of the CSEAC is to actively represent children and youth with disabilities and impact decisions made on their behalf to enhance the quality of educational services. The CSEAC is a state level committee mandated by federal and state law. Members include individuals with disabilities, parents of children with disabilities, service providers, administrators, and representatives of related agencies. Participation in the CSEAC is statewide and representative of diverse disabilities. The CSEAC welcomes guests to its meetings.

Roles for parents who serve on this committee include:

- Providing input and assistance to the state Board of Education;
- Advising the State Director of Special Education Services;
- Advocating for communication, cooperation, and partnership among education service providers, children and youth, parents, and administrators;
- Serving as a liaison among parents of children with special needs, local educational agencies, and the Special Education Services Unit of the Colorado Department of Education.

For information about CSEAC, check the CDE website (www.cde.state.co.us) or contact the 2000-2001 co-chairs:

Marcia Tewell/ Phone: (720) 941-0176 E-mail: marcia.tewell@state.co.us

LeeAnne Seaver/ Phone: (303) 639-5806 E-mail: tlseaver@earthlink.net

After May, 2001 contact the 2001-02 co-chairs:

Laney Heath/ Phone: (970) 241-6314 E-mail: relaxaranch@juno.com

Brett Prilik/ Phone: (303) 717-2370 E-mail: bprilik@denveryouth.org

Contractors

Parents might play a variety of leadership roles including:

- the ones who are contracted;
- members of the contracted team/project; and
- members of the project advisory council.

For information, contact:

Elizabeth Soper Hepp/ Phone: (303) 866-6711 E-mail: Hepp_E@cde.state.co.us

Romie Tobin/ Phone: (303) 866-6876 E-mail: romie_tobin@ceo.cudenver.edu

Evaluation Activities

Parents participate in on-site or other evaluation activities, such as Community Infant Services Review (CISR), Special Education On-Sites, or Early Childhood Collaborative On-Sites.

For information, contact:

Tom Patton/ Phone: (303) 866-6667 E-mail Patton_T@cde.state.co.us,
Rick Noll/ Phone: (970) 240-8181 E-mail rhino@gjct.net
Romie Tobin/ Phone: (303) 866-6876 E-mail romie_tobin@ceo.cudenver.edu

Learning Clusters

Parents might play a variety of leadership roles including participating as:

- learning cluster coordinators or co-coordinators;
- local planning team members (at least one parent is required by CDE to participate in the local planning of each learning cluster);
- participants in learning cluster activities, including those focused on parent leadership development;
- presenters and trainers for local and state learning cluster activities; and
- presenters and attendees at the annual Culture of Childhood Symposium.

For information about Learning Clusters, contact:

Jo Koehn/ Phone: (303) 866-6706 E-mail: Koehn_J@cde.state.co.us

Consolidated Child Care Pilots

There are consolidated child care pilot sites in 18 Colorado communities in 2000-2001. The purpose of these pilots is to coordinate all early childhood resources across the community and to identify and eliminate systemic barriers to quality comprehensive services for all children. Parents are needed to serve on local collaborative committees.

For information about Consolidated Child Care Pilots, contact:

Sharon Triolo-Moloney/ Phone: (303) 866-6781 E-mail: Triolo-Moloney_S@cde.state.co.us

For general information about parent leadership within CDE contact:

Elizabeth Soper Hepp
Phone: (303) 866-6711
E-mail: Hepp_E@cde.state.co.us

Romie Tobin
Phone: (303) 866-6876
E-mail: romie_tobin@ceo.cudenver.edu

Colorado Department of Education
201 E. Colfax Ave.
Denver, CO 80203-1799

Parent Leadership Opportunities at the Health Care Program for Children with Special Needs (HCP)

Parent participation is at the core of services provided to children with special health care needs through the Health Care Program for Children with Special Needs (HCP). In HCP, parents enjoy various roles. Parents:

- are hired to be part of multidisciplinary teams at state and regional levels;
- participate in planning, program development and evaluation of all programs within the HCP;
- participate on boards and committees that develop or review policies for children with special health care needs;
- present information about parenting children with special health care needs at conferences, in-service training, and other settings;
- provide parent-to-parent support, including support groups, for other parents;
- help to mediate complex systems issues that are challenging for parents seeking medical or payment services for their child;
- emphasize positive cultural, regional, and linguistic needs of families to ensure that services are developed to meet the needs of families;
- advise state level discipline consultants within HCP, (e.g. Occupational Therapy, Physical Therapy, Nutrition, Nursing, Social Work, Speech/Language Pathology, Care Coordination, Audiology, CHIP, provider concerns, and parent consultation);
- assist with outreach for assuring that other family members receive information on Medicaid resources;
- act as guides through the health care system based upon their personal experiences; and
- serve as advocates for systems change.

For general information about parent leadership opportunities with HCP, contact Kathy Watters at (303) 692-2418 or the regional office of HCP in your area.

Colorado Home Intervention Program (CHIP)

The Colorado Home Intervention Program (CHIP) is a family-centered, home-based early intervention program. CHIP provides interventions to families with young children who are deaf and hard of hearing and under the age of three. There is a variety of ways the parents participate in CHIP, including:

- parents receive a welcome letter from the CHIP Parent Advisor when they start receiving services from CHIP and may request information from the Parent Advisor about the etiology of their child's hearing loss, national and state organizations that have information specific to children who are deaf/hard of hearing, and parent organizations;
- parents can attend regional meetings and state meetings that emphasize issues specific to parents of deaf/hard of hearing children;

- parents can borrow information from the CHIP lending library and from the Colorado Clearinghouse;
- parents of deaf/hard of hearing children receive a copy of the newsletter from Colorado Families for Hands and Voices

For more information about CHIP, contact Janet DesGeorges at (303) 492-6283.

Developmental Evaluation (D & E) Clinics

The Developmental Evaluation (D & E) Clinics provide in-depth evaluation of all developmental areas (motor, perceptual, sensory, cognitive, emotional, psychosocial, and health) for children birth through 21 years who present the need for a diagnosis, particularly of major health issues. Parents can play a variety of leadership roles in the D & E Clinics, including:

- being hired to support families who are going through the D & E process;
- providing support to families in navigating follow-up suggestions which arise from the D & E.

For more information about the D & E Clinics, contact:

Paula Hudson

Phone and Fax: (303) 692-2413

E-mail: pbhudson@smtpgate.dphe.state.co.us

Colorado Department of Public Health and Environment,

FCHSD-HCP-A4,

4300 Cherry Creek Drive South

Denver, CO 80246-1530

Parent Leadership Opportunities at the Colorado Developmental Disabilities Planning Council

Parent and consumer participation in membership of the Colorado Developmental Disabilities Planning Council (Council) is mandated by the Developmental Disabilities Rights and Assistance Act. The Governor of Colorado appoints council members for three year terms. Vacancies on the Council normally occur each July. Parents may request an application from the offices of the Council or from the Governor's office. The Developmental Disabilities Rights and Assistance Act also requires membership on the Council from specific state agencies. However, at least 50% of the members of the Council must be people with developmental disabilities or parents of children with developmental disabilities. Parents can participate in Council activities in other ways as well.

For information on all Council activities, contact:

Phone: (720) 941-0176
CDDPC
3333 Quebec St., Suite 6009
Denver, CO 80207

Standing Committees

The Council has two standing committees. Please call for information on current committee opportunities. Parents are encouraged to join one of the Council's committees.

Task Forces

Throughout the year, the Council may form task forces to focus on specific issues. Interested parents are encouraged to participate in these as they happen.

Families Action Consortium

The Council is currently funding the Families Action Consortium for the purpose of involving families in public policy and legislative issues. The Council also funds what are termed unsolicited grants for various conferences including the Inclusion Conference, the Community Conference, El Grupo Vida Conference, Parent to Parent, Brain Injury Foundation, and Assistive Technology Conferences.

Requests for Proposals

The council issues requests for proposals, please call for details on the current priority areas. These are to develop pilot projects that can be replicated over time in the traditional system or may be folded into practice via legislation to help solve a variety of issues for persons with disabilities.

Consumer Involvement Fund

The Consumer Involvement Fund provides funds for people with disabilities, their family members or their guardians to participate in conferences, training events, public forums, task forces, hearings, and other similar activities. It is designed to empower people with disabilities and their family members with the opportunities, experiences, and information they need to meaningfully participate in the decisions that are being made which affect their lives. Limits on funds are \$400 per individual per year. There are times the Fund cannot support all of those who apply. Priority is given to first time users of the Fund. For more information about the Consumer Involvement Fund or to request an application, please call the Council offices.

Parent Leadership Opportunities at Children's Health and Rehabilitation Services

Children's Health and Rehabilitation Services is committed to parent and family involvement concerning services for children and adolescents. Parents and family members:

- participate in councils, committees, boards, and task forces;
- work as family advocates in local communities;
- provide training for parents and service providers on various topics; and participate on state-level efforts concerning the public mental health system.

For general information about parent leadership opportunities within Children's Health and Rehabilitation Services, contact William Bane at (303) 866-7406.

Parent Leadership Opportunities in Colorado's Community Mental Health System

Various opportunities for parent leadership roles within Colorado's community mental health system are described below.

Child & Family Committee (C&F Committee), and Colorado Mental Health Planning and Advisory Council (MHPAC)

Parents might play a variety of leadership roles including:

- general members of the Committee and/or the Council;
- co-chair of the Child & Family Committee; and
- member of work group concerned with a specific issue.

For information about the C & F Committee and MHPAC, contact William Bane at (303) 866-7406.

Training

Children's Health and Rehabilitation Services sponsors and provides training on a number of topics related to children's mental health. Parents:

- participate as trainers;
- assist in the development of training curricula; and
- become trained so that they can train others (training of trainers).

For information about Training, contact William Bane at (303) 866-7406.

Mental Health Assessment and Services Agencies (MHASAs) and Community Mental Health Centers (CMHCs)

Parents might play a variety of leadership roles including:

- Family Advocates (paid or volunteer);
- members of boards of directors or advisory groups;
- volunteers or mentors in local support and advocacy networks; and
- connections to other parent and family support activities in the local system of care.

For more information about MHSA and CMHC, contact (303) 866-7400 to be connected with the local MHSA or CMHC in your area.

Parent Leadership Opportunities in Colorado's Developmental Disabilities System

Most opportunities for parent leadership roles in the Developmental Disabilities system are available through the 20 Community Centered Boards (CCBs) throughout Colorado.

Family Support Councils

All CCBs have Family Support Councils, whose membership includes a majority of family members whose children have developmental disabilities or developmental delays. The Family Support Council Chairperson is always a family member, and Family Support Council members have significant opportunities to provide leadership in their local communities. Family Support Councils sometimes have sub-committees which include family members other than Council members. Contact the Family Support Coordinator in your local CCB for more information.

Other Opportunities

Other persons at CCBs who might be able to provide family members with information about local parent leadership opportunities are Early Childhood (or Early Intervention) Directors (birth-3) or Case Management Directors.

In addition, the following individuals may be able to provide family members with information about statewide opportunities for parent leadership:

Christine Collins, Colorado Association of Community Centered Boards (CACCB)
Phone: (303) 832-1618
E-mail: ccollins@caccb.org

Oxana Golden, Children and Families/Developmental Disabilities, Colorado
Children's Health and Rehabilitation Services
Phone: (303) 866-5943
E-mail: Oxana.Golden@state.co.us

John Miles, Training Programs Coordinator, Colorado Developmental Disabilities
Services
Phone: (303) 866-7459
E-mail john.miles@state.co.us

Information is provided on the following page for family members to locate and contact their local CCBs for assistance in identifying leadership opportunities in their local communities.

Community Centered Board	Counties Served	Address	Telephone/Fax
Arkansas Valley Community Center	Western Bent, Crowley, Otero	P.O. Box 1130 La Junta, CO 81050	(719) 384-8741 384-8173
Blue Peaks Developmental Services	Alamosa, Conejos, Costilla, Rio Grande, Mineral, Saguache	703 Fourth Street Alamosa, CO 81101	(719) 589-5135 589-0680
Centennial Developmental Services	Weld	1050 37th Street Evans, CO 80620	(970) 339-5360 330-2261
Colorado Bluesky Enterprises	Pueblo	115 West 2nd Street Pueblo, CO 81003	(719) 546-0572 546-0577
Community Connections	Archuleta, Dolores, La Plata, Montezuma, San Juan	281 Sawyer Dr. #200 Durango, CO 81301	(970) 259-2464 259-2618
Community Options	Delta, Gunnison, Hinsdale, Montrose, Ouray, San Miguel	P.O. Box 31 Montrose, CO 81402	(970) 249-1412 249-0245
Denver Options	Denver	5250 Leetsdale Dr. #200 Denver, CO 80246-1438	(303) 753-6688 753-6364
Developmental Opportunities	Chaffee, Custer, Fremont	P.O. Box 2080 Canon City, CO 81215	(719) 275-1616 275-4619
Developmental Pathways	City of Aurora, Arapahoe, Douglas	11111 E. Mississippi Ave. Aurora, CO 80012	(303) 360-6600 341-0382
Developmental Disabilities Center	Boulder	1343 Iris Street Boulder, CO 80304	(303) 441-1090 441-1298
Develop. Disabilities Resource Center	Clear Creek, Gilpin, Jefferson, Summit	7456 W 5th Ave. Lakewood, CO 80226	(303) 233-3363 233-4622
Eastern Colorado Services	Cheyenne, Elbert, Kit Carson, Lincoln, Logan, Morgan, Phillips, Yuma, Sedgwick, Washington	P.O. Box 1682 Sterling, CO 80751	(970) 522-7121 522-1173
Foothills Gateway	Larimer	301 Skyway Drive Fort Collins, CO 80525	(970) 226-2345 226-2613
Horizons Specialized Services	Grand, Jackson, Moffat, Rio Blanco, Routt	P.O. Box 774867 Steamboat Springs, CO 80477	(970) 879-4466 870-0334
Mesa Developmental Services	Mesa	P.O. Box 1390 Grand Junction, CO 81502	(970) 243-3702 243-7751
Mountain Valley Developmental Services	Eagle, Garfield, Lake, Pitkin	P.O. Box 338, Glenwood Springs, CO 81602	(970) 945-2306 945-6469
North Metro Community Services	Adams, Broomfield	1001 W. 124th Ave. Westminster, CO 80234	(303) 457-1001 457-2326
Southeastern Developmental Services	Baca, Kiowa, Prowers, Eastern Bent	P.O. Box 328 Lamar, CO 81052	(719) 336-3244 336-3898
Southern Colorado Developmental Disabilities	Huerfano, Las Animas	P.O. Box 781 Trinidad, CO 81082	(719) 846-4409 846-8329
The Resource Exchange	El Paso, Park, Teller	418 S. Weber St. Colo. Springs, CO 80903	(719) 380-1100 380-1108

2025-2026 AVAILABLE

Parent Leadership Opportunities at JFK Partners, University of Colorado Health Sciences Center

JFK Partners is an interdepartmental center of Pediatrics and Psychiatry in the School of Medicine at the University of Colorado Health Sciences Center. The mission of JFK is to promote the independence, inclusion, contribution, health and well-being of people with disabilities. At the core of this mission is a commitment to family/person-centered, community-based, and culturally competent programs and services. This mission is accomplished through the pursuit of excellence in education/training, consultation, technical assistance, direct service, research, program development, policy analysis, and advocacy. Parents are invited to participate in programs in many ways, including: planning, developing, and evaluating programs and services; teaching and training workshops and classes; and serving on task forces and committees.

For more information on the opportunities described below, or for general information on parent leadership opportunities at JFK Partners, contact Tracy Price Johnson, unless specified otherwise, at:
Phone: (303) 315-6527
E-mail: Tracy.Johnson@uchsc.edu

Education

JFK Partners offers parents opportunities to attend a variety of educational activities. Among these opportunities is a collaborative program with the Colorado Department of Education, through which a ten month training program on Teaming, Collaboration, and Leadership is available to a limited number of parents.

For more information contact Larry Edelman at (303) 864-5264
E-mail: edelman.larry@tchden.org

JFK Partners Family and Self-Advocate Support Team

This team is an integral part of JFK Partners' efforts to insure family-centered and community based perspectives through all of its activities. The team interfaces with other parent and consumer groups throughout the state in order to keep abreast of activities and events, as well as bringing in cutting edge leaders to dialogue with families at JFK and other organizations. The team offers a strong voice at faculty meetings and is represented on other standing and ad hoc committees at JFK Partners. Among many other activities, the team provides support for JFK's Consumer Advisory Council.

Consumer Advisory Council

Parent leadership is encouraged through JFK's Consumer Advisory Council. The twenty-member Council is a forum through which project leaders present

their work and receive feedback and suggestions for future direction. This group is comprised of self and family advocates as well as advocates from state organizations who have participated in JFK Partners' programs and who offer valuable expertise to overall strategic planning and programming.

Colorado Parent Leadership Development Programs

The purpose of the projects described in this section is to support family members in developing their leadership skills.

The Advocacy Project

- Background:** The Advocacy Project was started in 1999 out of the need for parents and advocates to have more consistent information. The training curriculum was developed by focus groups and has increased to a total of 27 class offerings. Participants may earn a certificate in education advocacy or increase their knowledge to benefit their own family.
- Goals:** The Advocacy Project (TAP) works in partnership with parents, advocates, educators, and community organizations to provide coordinated resources, training, information, networking, and leadership to maximize advocacy efforts for at risk students from pre-school through post secondary opportunities.
- Format:** The Advocacy Project has on-going classes in education advocacy offered statewide for parents, educators, and advocates. Whether parents want to advocate for their own family or offer their advocacy expertise to others, The Advocacy Project is where to learn best practices, the law, and "how to" in working with schools and school districts.
- The Advocacy Project classes are designed to be advanced "hands-on" and practical sessions that will give participants action steps that can be taken immediately to improve education for students with IEP's and 504 Plans. The classes consist of guest speakers and lively discussion. Other services offered include an advocate referral list, newsletter, advocacy information and referral, web based research, website resources and watch for our website coming soon.
- Participants:** Parents, educators, and advocates.
- Funding:** The Advocacy Project is funded through government grants, corporations, foundations, and participant fees. Family scholarships are available.
- For more info:** To locate or sponsor classes in your community, contact Lee Mizer at (303) 680-6741 or AdvocacyPro@aol.com

The Coaching Project

Background: The Colorado Department of Education (CDE) was looking for a different strategy to further the goals of developing parent leadership in Colorado. The concept of coaching was growing nationally, primarily in the field of business as a structure to support professionals in focusing and succeeding in creating the changes they wanted to make. Coaching is guided process for achieving any kind of result, in this case parent leadership. CDE wanted to focus on the natural strengths which parents have, and support them in charting their path. CDE was interested in supporting a long-term strategy where parents could test out ideas that were important to them, practice skills, set goals, then learn from their experience. CDE chose to fund the development and implementation of a variety of coaching strategies, including individual coaching, workshops, and other opportunities which parents co-created together. The project was named "The Coaching Project."

Goals: The purpose of this project is to support and enhance parent leadership throughout Colorado. This project focuses on a model that uses coaching to assist parents of children with disabilities in developing their own leadership skills. The project supports leadership of parents to promote inclusive communities and the provision of supports and services in natural environments.

Format: There are many opportunities for parents of children with disabilities to become enthused about the possibilities of creating change in their child's life, their own lives and their communities. Parents report that the acquisition of coaching skills enhances their ability to interact with professionals and systems in creative ways. The outcomes for children are enhanced by parents being able to support the creativity of the professionals and community leaders that interface with their child and family. Acquisition of coaching skills allows parents to support others in creative problem solving and moving to action rather than wasting time and energy in collect and stand off. This project provides that follow-up. Coaching provides parents with the support they need to move forward in pursuing their dreams.

Specific opportunities available through The Coaching Project include:

- **Workshops:** Today, families report increased stress, isolation, frustration, and feeling overwhelmed. Leadership I & II is a series of family friendly workshops aimed at creating more balance in daily life, prioritizing and living a more fulfilling life, and expanding visions of everyday living.

Workshops are available in a 2 hour, 4 hour, and 6 hour model. The choice is yours – workshops are free.

- **Coaching:** Participate in an 8-week Coaching relationship. This is like having your own personal trainer for the journey of your life; someone who will help you find your way and stay on course. Coaching is free.
- **Teleclasses:** Teleclasses are live interactive conversations over the telephone through state of the art teleconferencing bridge systems. During a teleclass you will receive timely tips, tools, strategies, and techniques that can benefit your life, your role as a parent, and your leadership capacity immediately. Teleclasses are convenient. You can call from the comfort of your home or office while eliminating travel time and expenses.

Participants: Parents of children with disabilities.

Funding: This program is currently funded the Colorado Department of Education, Part B and Part C.

For more info: Contact Sandy Scott and Associates, 1808 Centennial Rd., Fort Collins, CO 80525
Phone: (970) 266-1344 Fax: (970) 266-6025
E-mail: Coachsys@earthlink.net
<http://home.earthlink.net/~coachsys/>

Family Advocacy Curriculum

Background: The development of the "Bone Deep" family advocacy curriculum began in 1996 and was initiated by the Colorado Department of Human Services (CDHS). The need for an intensive training on family advocacy resulted from the family support movement of the 1980's. During this decade, community-based initiatives began to change how social problems, such as homelessness, child abuse, and poverty were addressed. There was a grassroots movement away from crisis-based, deficit-oriented services toward prevention-oriented, community-based, family support practices. In Colorado, this movement created challenges for practitioners as they concurrently tried to provide services to families while learning how to implement family support practices. The CDHS staff repeatedly heard from practitioners, working in state-funded family support programs, that a training was needed to build skills in providing strength-based, capacity-building services to families.

The "Bone Deep" training was originally offered through the Colorado Department of Human Services between 1997 and 1998. During this period, over 100 family advocates completed the training. Today the "Bone Deep" training is

delivered through the Colorado Family Resource Network and the trainers include individuals who have completed the "Bone Deep" training, and are family support practitioners and advocates.

- Goals:** "Bone Deep 101" The first training is designed to introduce participants to core concepts related to family support and family advocacy. There is a focus on use of self in the family advocacy process and working with diverse families one on one. The 101 training also examines how to work collaboratively with systems to provide services to families.
- "Bone Deep 102" The second training module builds on the information presented in 101 and takes a broader look at family support. This training expands from working one on one with families to working with diverse families in groups. Participants move from working with systems to working with communities. Information on community organizing, and creating and utilizing community partnerships is offered in 102.
- After completing both modules of the training, participants will have a comprehensive awareness of family support and have a great understanding of how to implement family support practices.
- Format:** it is currently designed to be delivered in four, two-day sessions. The "Bone Deep" *Family Advocacy Curriculum* is intended to train family advocates in a variety of human service organizations.
- Participants:** Family and community advocates, and other practitioners engaged in working directly with families.
- Funding:** In 1996, CDHS and the Colorado Family Resource Network (CFRN) were selected to participate in the Family Resource Coalition of America's initiative, now known as Family Support America, which is generously funded by the Robert Wood Johnson Foundation.
- For more info:** Contact: Virginia Martinez at (303) 837-8466 ext. 112 or e-mail at virginiam@what-works.org

Mobilizing Families

- Background:** Mobilizing Families has been in existence since 1989. Since the beginning of the program, at least 350 people have gone through the training. In 1999, the Arc recognized Mobilizing Families for excellence at both the State and National Level.
- Goals:** To help families see themselves as a valuable resource; to help families know what their community offers before looking at specialized services; to help families know what specialized services exist; to help families be able to make systemic change.
- Format:** Eight, once-weekly sessions from 6:30 p.m. - 9:00 p.m. over eight weeks (the particular day is given to change). Offered one time a year, with 12 - 30 participants. In the development stage is Mobilizing II which is being designed for families that have an adolescent transitioning into the Adult System.
- Participants:** Parents of children with disabilities.
- Funding:** This program is currently funded by Arc of Jefferson County.
- For more info:** Contact Jo Lynn Osborne, The Arc in Jefferson County, 8725 West 14th St., #100, Lakewood, CO 80215. Phone: (303) 232-1338. Fax: (303) 232-9370. E-mail: jolynn@arcjc.org

Parents Encouraging Parents (PEP)

- Background:** Parents Encouraging Parents has been offering conferences for families since 1980, throughout the state of Colorado. During that time, over 7000 individuals have attended PEP.
- Goals:** To offer support, information, and education to parents and professionals; to promote the partnerships that are essential in supporting and including children with disabilities and their families in all aspects of the school and community.
- Format:** Two and a half day workshop/conference held Thursday evening through Saturday for 150 participants. Held in 3 different state locations annually.
- Participants:** Parents of children birth to 21 years old (single parents can bring one support person if they wish); school personnel including principals, superintendents, teachers.
- Funding:** This program is currently funded by the Special Education Services Unit and Early Childhood Connections at the Colorado Department of Education.
- For more info:** Contact Parents Encouraging Parents at (303) 866-6846.

Policymakers

- Background:** Policymakers began operating on April 1, 1997.
- Goals:** To develop a statewide network of persons with disabilities and family members of persons with disabilities designed to effect systemic change.
- Format:** A two-hour "Best of Policymakers" presentation is available until June 30, 2001.
- Participants:** Persons with disabilities and family members who want to create systemic change and are willing to make a long-term commitment to being part of a statewide network.
- Funding:** This program is currently funded by DDPC, United Cerebral Palsy (UCP), and small foundations.
- For more info:** Contact Robin Bolduc or Bruce Goguen at (303) 691-9339 or (800) 881-8272. Fax: (303) 691-0846. Address: 2200 S. Jasmine Street, Denver, CO 80222. E-mail: policy@ucpco.org

Other Colorado Resources Related To Parent Leadership Development

In addition to the programs described previously, there are several other notable initiatives that, while not necessarily focusing directly or exclusively on parent leadership, are naturally connected to parent leadership efforts. The list of programs described in this section is far from exhaustive, but gives an idea of the kinds of resources currently available.

Arc of Colorado

The Arc of Colorado is a membership-based organization created in 1957 by parents to improve the quality of life for all people with developmental disabilities and their families. The Arc provides a variety of advocacy services including public information and education, training, technical assistance, referral, and individual and class/system advocacy.

For more information, contact: The Arc of Colorado. Phone: (303) 864-9334. Address: 777 Grant St., Suite 303, Denver, CO 80203. E-mail: info@thearcofco.org

Colorado Family Resource Network

Formed in 1995, Colorado Family Resource Network (CFRN) is a statewide membership based family support network dedicated to building the capacity of its members to support and strengthen families. CFRN accomplishes this mission through training, technical assistance, advocacy and resource information. CFRN is a project of the Colorado Foundation for Families and Children.

For more information, contact Virginia Martinez (303) 837-8466 ext. 112 or e-mail virginiam@what-works.org

Colorado Family Voices

Family Voices is a national grassroots organization composed of families and professional friends who care for and about our children with special health care needs. Family leaders from around the nation organized Family voices in December 1992 to ensure that our children's health is addressed in family centered ways as public and private health care systems undergo change in communities, states, and the nation. We speak on behalf of our children so that their health and well-being, and that of their families, is of a quality fitting this nation. The Family Voices Chapter in Colorado is committed to assist families with access to healthcare, advocating for healthcare and educating providers, parents, and consumers about healthcare.

For more information contact one of the co-coordinators: Christy Blakely, phone (303) 973-5780, fax (303) 973-4988, e-mail Christy957@aol.com or Lori Park, phone (303) 447-8447, e-mail LParkpris@aol.com

Denver Community Leadership Forum

The purpose of the Denver Community Leadership Forum (DCLF) is to provide participants with a learning laboratory that teaches skills and shares knowledge about leadership and the collaborative problem-solving process. It annually brings together groups of emerging leaders drawn equally from the public, private, and community/nonprofit sectors to focus on the key skills required of today's community leaders: consensus building, conflict management and resolution, team building, and facilitation. The result is a network of empowered, effective leaders in our community.

Participants interact with respected academics, experts in leadership skill building and consensus building, alumni of the program, and acknowledged leaders who are willing to share their own expertise and knowledge. The program is complemented by a five-day Outward Bound course, designed specifically for DCLF participants, which develops teamwork and builds confidence. The 30 participants in each annual program meet once per month for one to two days at a time, and for five days at the Outward Bound seminar. The program begins in February and concludes in November. Program alumni then join a network of community leaders who are skilled at collaborative problem solving and are an extraordinarily effective resource for the Denver community. **For more information**, contact Louise Ninneman, DCLF Program Director, Center for Public Private Sector Cooperation, 1445 Market ST., Suite 380, University of Colorado at Denver, Denver, CO 80202. Phone (303) 820-5667 or e-mail lninnema@carbon.cudenver.edu

El Grupo VIDA

El Grupo VIDA is a support network for families who are monolingual Spanish speaking and who have a child with special needs. The group meets every third Thursday of January, March, May, September, and November, and hosts a family picnic in July, a Thanksgiving potluck, and a conference totally in Spanish. El Grupo VIDA has been in existence for nine years.

For more information, contact their voicemail at (720) 932-1428, or fax (303) 295-7850. Address: P O Box 16347, Denver, CO 80216.

Parent Leadership Training

The Parent Leadership Training is a curriculum that introduces parents to skills and knowledge necessary for becoming an advocate for their, and all children. The curriculum stresses the strengths that families bring to the leadership process. Organizations or communities can contact the Center for Human Investment Policy to discuss how to bring this training program to the parents in their local area.

For more information, contact Tina House at (303) 820-5636 or e-mail: thouse@carbon.cudenver.edu

Parent Surrogate Program

Training is provided for parents who will be acting as Surrogate Parents under IDEA legislation for children with IEPs whose parents are deceased, cannot be located, or are in the Social Services System. A database is being compiled of all certified surrogate parents and will provide follow-up support.

For more information about the Surrogate Parent training program for Early Childhood Connections **under part C of the IDEA** for children from birth to age 3, contact Randy Chapman of The Legal Center at (303) 722-0300 or e-mail at rchapman@thelegalcenter.org

For information about Surrogate Parent Training **for part B of the IDEA** for children ages 3 to 21, contact your local school district's Director of Special Education or Charles Masner at Colorado Department of Education at (303) 866-6685 or e-mail at masner_c@cde.state.co.us

Parent to Parent of Colorado

Parent to Parent of Colorado is a parent initiated, controlled, and organized group of over 550 families across the state. The mission of Parent to Parent is to build inclusive communities, take effective group action, and support each other on the journey of parenting our sons and daughters with special health care needs or disabilities. At Parent to Parent, the top priority is connecting families in Colorado to the people and information they need. Whether they are the parents of an adult, and adolescent, or a newborn, Parent to Parent is available to make those important connections.

Parents stay connected to one another by one-on-one matching of new parents and veteran parents through their toll free phone line (1-877-472-7201), a listserv that allows parents to share information over the Internet (P2P-CO@egroups.com), and cluster groups that meet in different areas of the state. Parent to Parent of Colorado has helped parents find information on a variety of issues ranging from hip surgery to respite care to wheelchair accessible vacation spots. They have also matched families that have sons and daughters with rare and unusual medical diagnoses. Through their database, they have found other parents in Colorado with whom unique experiences can be shared.

For more information, contact Parent to Parent of Colorado at 1-877-472-7201, fax (719) 336-2389, e-mail parents@ucpc.org

PEAK Parent Center, Inc.

PEAK (Parent Education And Assistance For Kids) has as its mission "to ensure that children, youth, and adults with disabilities lead rich, active lives and participate as full members of their schools and communities." PEAK is involved with a broad array of services and programs for families of children with disabilities. Some programs include: a toll-free parent information hotline; community training and workshops; the SPEAK OUT newsletter; a monthly events calendar; and the Conference on Inclusive Education in Colorado. PEAK Parent Center publishes several inclusion resources for families and educators which offer practical strategies for including students with disabilities in general education classrooms.

**For more information, contact (719) 531-9400 or (800) 284-0251 or
E-mail: info@peakparent.org website: www.peakparent.org**

Teamwork, Consultation, and Leadership Dialogues Course

Having been in existence for four years, this interdisciplinary course is offered by JFK Partners in the University of Colorado Health Sciences Center. The course focuses on teamwork, consultation, and leadership skills needed for providing family-centered, culturally competent, community-based services for children with special needs and their families. The class meets for 2 hours every Friday from September - May and includes an 8 hour per week practicum. Federal grants fund the participation of practitioners and the Colorado Department of Education funds the participation of parents in the program.

For more information, contact Larry Edelman at (303) 864-5264 or E-mail: edelman.larry@tchden.org

Colorado Disability Related Groups

There are a number of disability related organizations in Colorado. These various groups might provide support, information, and other resources for families who are interested in particular issues. Below is a listing of such groups.

American Council of the Blind

1201 E. Colfax, Suite 250
Denver, CO 80218
(303) 831-0117

American Diabetes Association

Colorado Affiliate
2480 W. 26th Ave., Suite 120B
Denver, CO 80211
(720) 855-1102 or (800) 7822873
Fax: (720) 855-1302
www.diabetes.org

Arthritis Foundation

2280 S. Albion St.
Denver, CO 80222
(303) 756-8622
Fax: (303) 759-4399
www.arthritis.org

Autism Society Colorado Chapter

5031 W. Quarles Drive
Littleton, CO 80128-6415
Phone/Fax: (303) 978-1440
www.autismcolorado.org
E-mail: asacc@autismcolorado.org

Brain Injury Association of Colorado

4200 W. Conejos Pl. #524
Denver, CO 80204
(303) 355-9969
(800) 955-2443
Fax (303) 355-9968
www.BIAColorado.org
BIAColo@aol.com

Center on Deafness

1490 Lafayette #40
Denver, CO 80218
(303) 839-8022
Fax: (303) 839-8027
www.centerondeafness.org
E-mail: cod@pcisys.net

Colorado Cross Disability Coalition

655 Broadway, Suite 774
Denver, CO 80203
(303) 839-1775
Fax (303) 839-1782
TTY (303) 839-0015
www.colorado2.com/ccdc
ccdc1997@aol.com

Colorado Families for Hands and Voices

(for families of children who are deaf/hard of hearing)
P.O. Box 371926
Denver, CO 80237
www.handsandvoices.org

Colorado Spina Bifida Association

PO Box 22994
Denver, CO 80222
Voice Mail: (303) 423-0096
e-mail: info@coloradospinabifida.org
www.coloradospinabifida.org

Coloradoans for Family Support

PO Box 563
Louisville, CO 80027
(303) 665-3897

Colorado Parents of Blind Children

2233 W. Shepperd Ave.
Littleton, CO 80210
(303) 778-1130
fax (303) 778-1598
E-mail: jhunter@ccb-denver.org
www.nfbc-denver.org

Concerned Parents

(parent support group)
17355 W. 57th Avenue
Golden, CO 80403
(303) 271-9628
Fax (303) 277-9757

Easter Seals Colorado
5755 W. Alameda Ave.
Lakewood, CO 80226
(303) 233-1666
Fax (303) 233-1028
www.eastersealsco.org
steerst@cess.org

Epilepsy Foundation of Colorado
234 Columbine St. #333
Denver, CO 80206
(303) 377-9774
1-888-378-9779 (Colorado toll-free)
Fax (303) 377-9774
EFCO@msn.com
www.epilepsycolorado.org

Families First Support Line
(303) 695-7996
10 a.m. to 10 p.m. 7 days a week

Federation of Families for Children's Mental Health
901 W. 14th Ave.
Denver, CO 80204
(303) 572-0302
Fax (303) 572-0304
1-888-569-7500
www.coloradofederation.org

Fetal Alcohol Syndrome/Drug Exposed Support Group
3442 S Vrain
Denver, CO 80236
(303) 936-2063
E-mail: mklene@dnvr.uswest.net
www.uchsc.edu/ahec/fas

Foundation Fighting Blindness Support Group
6920 Hillridge Place
Parker, CO 80134
(303) 841-4202
Fax (303) 841-8454
E-mail: Kathy@tma-cpro.com

Fragile X Support Groups
Metro Denver: (303) 973-3581
Colorado Springs & Southern: (719) 598-0983
Northern Colorado: (970) 669-3147
Mountain Area: (970) 926-3210

Learning Disability Association of Colorado
4400 E. Iliff Ave.
Denver, CO 80222-6019
(303) 894-0992
Fax (303) 830-1645
ldac@uswest.net

Legal Center for People with Disabilities and Older People
455 Sherman St., Suite 130
Denver, CO 80203
(303) 722-0300 or (800) 288-1376
Fax: (303) 722-0720
www.thelegalcenter.org

Leukemia & Lymphoma Society
5353 W. Dartmouth Ave.
Denver, CO 80227
(303) 293-8300 or (800) 286-8159
www.leukemia-lymphoma.org

The Listen Foundation
3701 S. Clarkson St., Suite 330
Englewood, CO 80010
(303) 781-9440
Fax: (303) 781-2018
E-mail: lstnsoun@aol.com
www.listenfoundation.org

Mental Health Association of Colorado
6795 E. Tennessee Ave., #425
Denver, CO 80224
(303) 377-3040
Fax (303) 377-4920
www.mhacolorado.org

Mile High Down Syndrome Association, Inc.
PO Box 620847
Littleton, CO 80162
(303) 797-1699
Fax (303) 336-5669
E-mail: mhdsa@aol.com
www.mhdsa.org

Muscular Dystrophy Association
720 S. Colorado Blvd., Suite 450 S
Denver, CO 80246
(303) 691-3331
Fax (303) 691-3379
www.mdausa.org

**National Alliance for the Mentally Ill
of Colorado (NAMI Colorado)**

1100 Fillmore Street
Denver, CO 80206
(303) 321-3104
fax (303) 321-0912
toll free 1-888-566-6264
E-mail: nami-colorado@NAMI.org

**Neurofibromatosis Chapter Support
Groups**

P.O. Box 101357
Denver, CO 80250-1357
(303) 460-8313
fax (303) 460-1421
e-mail: usrkids@aol.com

Senior Vision Connection Program

3850 Alcott
Denver, CO 80211
(303) 433-1500
Fax (303) 433-2109

Speaking for Ourselves

899 Logan, #311
Denver, CO 80203
(303) 831-7733

**Tourette Syndrome Association
Rocky Mountain Region**

1045 Lincoln St., Suite 102
Denver, CO 80218
(303) 832-4166

Turner Syndrome Society

5201 S. Quebec
Englewood, CO 80111
(303) 256-5631
E-mail: jemmarketing@gateway.net
www.turner-syndrome-us.org

**United Cerebral Palsy of Colorado,
Inc.**

2200 S. Jasmine St.
Denver, CO 80222
(303) 691-9339
Fax (303) 691-0846
(800) 881-8272
www.ucpc.org
e-mail: tnaylor@ucpc.org

Unlimbeted Child

12815 E. Nevada Ave.
Aurora, CO 80012
(303) 344-8773
or 1323 Swallow Ct.
(303) 443-1866

Even More Opportunities for Parent Leadership

Most of the organizations mentioned so far in this guide are somehow related to children with special needs. Because of successful efforts to promote inclusive communities and the provision of supports and services in natural environments, children with special needs increasingly enjoy the full richness of community life. This gives parents of children with special needs the opportunity to provide leadership for a host of typical community activities for children. Below is a list of some of these opportunities. Contact information can be found in most telephone books.

- Boys & Girls Clubs of America
- Boy Scouts of America
- Campfire Council of Colorado
- Girl Scouts of the USA
- Colorado Statewide Parent Teacher Associations and Organizations
- School Building Accountability Committees
(contact the principal of your neighborhood school)
- Little League and other community sports organizations
- Religious Organizations
- YMCA's and YWCA's
- Parks & Recreation Sports & Activities

Some Strategies for Successful Participation on Advisory Groups, Boards, and Work Groups

Ask questions to decide if you want to participate:

- What is the purpose of the group?
- How much time will this take? How frequent are the meetings? Will this be an ongoing committee or will it be short term?
- Will it involve travel?
- What is the ratio of providers or professionals to family members and self-advocates?
- How are family members and self-advocates selected for participation?
- What is my role?
- Do they provide the information, support for me to participate effectively?
- Is reimbursement available for your time and expenses (e.g., travel & per diem, postage, copying, phone calls, child care) Is it available ahead of time?

Recognize the Supports You Might Need

- Adequate reimbursement.
- A clearly identified person to assist with reimbursement and other issues.
- Adequate orientation to the issues, participants, and process.
- Mentoring from an experienced family member or self advocate.
- Accurate, timely, clear, and appropriate information.
- Option to be put on mailing lists in order to receive pertinent information.
- Clear information about the goal of the committee and your role.
- Opportunities for the development of meaningful relationships.
- Opportunities to network with their peers in other states or locales (e.g., conferences, conference calls, planning committees, etc.).

Institute for Family Centered Care Publications

The Institute for Family-Centered Care has published several books useful to parent leaders and those who support parent leadership.

***The Parent Leadership Program Training Manual* (1996)**

by Joan Blough, Patt Brown, Sharon Dietrich, and L. Bryn Fortune.

This book is a curriculum developed by Early On Michigan, Michigan's Part C Program, to train parents in early intervention leadership.

***Essential Allies: Families as Advisors* (1995)**

by Ibby Jeppson and Josie Thomas

This book was developed to help equip providers to work more effectively and collegially with families at the program and policy level.

***Words of Advice: A Guidebook for Families Serving As Advisors* (1997)**

by Josie Thomas and Ibby Jeppson

This book offers guidance for thinking through the benefits and demands of advisory roles for consumers, presents some fundamental principles for being a successful advisor, and suggests practical tips for dealing with the common challenges that families encounter in these new roles.

***Families as Advisor: A Training Guide for Collaboration* (1997)**

by Ibby Jeppson and Josie Thomas

This publication offers a set of training activities to encourage dialogue and promote creative thinking about partnerships between parents and providers.

For more information contact:

Institute for Family-Centered Care
7900 Wisconsin Ave., Suite 405
Bethesda, MD 20814
Phone: (301) 652-0281
E-mail: ifcc@aol.com

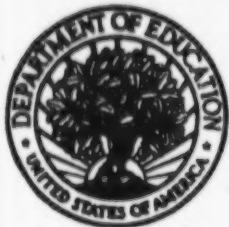
*About
Early Childhood Connections,
Colorado Department of Education*

Part C of the Individuals with Disabilities Education Act (IDEA) is a federal program that assists states in operating a system of early intervention supports and services for infants and toddlers with disabilities, ages birth through age two years, and their families. In Colorado, the Part C initiative is called Early Childhood Connections. As the lead agency, the Colorado Department of Education is charged with implementing Early Childhood Connections (ECC), the statewide, comprehensive, coordinated system of supports and services for infants and toddlers with developmental delays and their families. Early Childhood Connections operates under a grant from the U.S. Department of Education, # H181A990097. For more information about Early Childhood Connections:

Colorado Department of Education
201 E. Colfax Ave.
Denver, CO 80203-1799
(303) 866-6710

Visit the ECC web site: www.cde.state.co.us/earlychildhoodconnections

Contact 1 (888) 777-4041 to be connected with the local Early Childhood Connections office in your area.



U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)



NOTICE

Reproduction Basis

X

This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

☐ This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").